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ABSTRACT

This paper presents a summary of a qualitative research study which evaluated, in case studies of three families, what it means to have a child with a disability. The research developed out of practice in early intervention and work focusing on optimal developmental environments for persons with disabilities. Background information on each of the families is provided, including data on the children's disabilities, which included mental retardation in each case. Five principal areas which emerged from interview data are identified: the children, parental stress/anxiety, services, personal comments, and survival strategies. Data acquired from questionnaires completed by the parents and from the MAPS (McGill Action Planning System) planning process are also presented. Recommendations are provided in three areas: attitude changes, policy changes, and service provision. (Contains 14 references.) (JDD)

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CHILD DISABILITY: A STUDY OF THREE FAMILIES

(Summary)

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CHILD DISABILITY: A STUDY OF THREE FAMILIES
(Summary)

This research developed out of practice in early intervention and work focussing on optimal developmental environments for persons with disabilities. It has become very clear over the last decade that parents must be involved in the decision-making, planning and implementation of interventions for young disabled children (Bloom, 1986; Bailey, 1987; Bailey and Simeonsson, 1988; Dunst, 1985; Dunst, Trivette and Deal, 1988). It seemed logical, to me, that the same could be said for all parents of dependent children, particularly those of children requiring special intervention programs. In other words, what is regarded as good for parents and children in early intervention programs, is likely good for all children and especially for all children with special needs, whether they are in early intervention, elementary or secondary school, or are postschool-aged adults with disabilities, who are living in their parental homes.

What about the task of working with parents? How do we go about it? What would be helpful? What should be avoided? Following in the best tradition of Carl Rogers, the focus of this study is on the people who can best help professionals understand how to work with parents of children with disabilities, the parents themselves.

Concurrently, there is growing interest in qualitative research (Bogdan & Biklen, 1988; Yin, 1984; Lincoln and Guba, 1985; Stainback & Stainback, 1988). Some research questions are best answered by qualitative research methods and procedures. The exploration of how professionals can best work with parents of children with disabilities is a one of these. The basic research question for this study is: What does it mean to a family to have a child with a disability? Solutions to practical problems will likely develop out of a better understanding of the answer to this question.

Methods and Procedures

This research consists of individual case studies of three families, each with a child with disabilities. The mothers of each family are the "principal informants" but are regarded as co-researchers. This study is their study. I am simply the mechanism through which each mother tells the story of her family.

I obtained the first mother's name from a provincial advocacy group for persons with mental retardation. She was very interested in the study and found two additional mothers equally interested in taking part in the research. These three mothers were interviewed on two separate occasions.

Philosophically, the first interview made this request: Tell me what I need to know (about what it means to have a child with disabilities in your family). The second interview delved more deeply into topics or items presented by the mother in the first interview and

also explored the personal meaning of the children's disabilities for each mother. Planned questions were prepared for each interview, but co-researchers was free to take each interview in any direction or onto any topic that she chose.

In total, the study incorporates about five hours of interview data from each mother. Interviews were taped, transcribed, and then analyzed for emerging themes. Co-researchers checked all narratives and analyses in every stage of the research. This research is a collaborative effort.

Additional data were gathered in order to obtain information from fathers and selected others and to verify what was obtained from the mothers. These were gathered by questionnaires (see Dunst, Trivette and Deal, 1988) followed by a discussion with both parents of the questionnaire data and analyses, and a planning session with the family using MAPS (Forest and Lusthaus, 1989, 1990) as the planning instrument. Observations were made of each family at every session and in informal social settings.

Data were gathered from September to December, 1991. Some co-researcher checking of data and analyses took place during that time, as well. Writing and co-researchers' checking continued until April of 1993. The final report of the project was available by May of 1993 (Bloom, 1993).

Findings

1. Histories

a. Family #1

Martha and David are 37 and 46 years old, respectively. She is a nursing instructor at a technical college and he is a university research technician. They have been married for about 10 years. This is the second marriage for both partners. Bruce is David's youngest natural child. He is 18 years old and would probably be designated as severely mentally retarded. In general, Bruce displayed behaviors early in life that indicated developmental delay and neurological damage, with seizures. David's first marriage ended early in Bruce's life and custody of him and his two older brothers was awarded to their natural mother. When Bruce was four years old, she placed him in a residential institution where Martha was one of his caregivers. In the years following Bruce's placement in the residential institution, David and Martha met and later married. When Bruce was nine years old, David started legal proceedings to gain custody of Bruce. After two years of struggle, David was awarded custody in an out-of-court settlement. By that time David and Martha had been married and Bruce came to live with them.

It was at that time that Bruce first received his experience of public school. He spent a year in a segregated special class at the elementary school level and then was placed in a junior high school

special class. By the last year of junior high school he had a "Circle of Friends" (Forest and Lusthaus, 1989; Perske, 1988) and spent about 50% of his time in regular classrooms. David and Martha had hoped that this type of programming would continue at the senior high school level; but such has not been the case. This disappointment in the kind of educational programming for Bruce along with Bruce's very serious illness last year, were a source of recent extra stress for this family.

b. Family #2

Anne and Sam are 38 and 42 years old, respectively. She is a laboratory technician, unemployed at the time of this study, and he is a fire Chief. They have been married for about 15 years and have three children: Wayne, age 13; Terrance, age 10; and Marianne, age 9.

When Marianne was only a few days old, she was identified as having Down syndrome. In addition, she was born with two dislocated hips and a heart defect. The hips were repaired through bracing and physical therapy and the heart defect was repaired by open heart surgery, done when Marianne was five years old. From birth until her heart surgery, Marianne experienced many illnesses, mostly having to do with respiratory infections and croup. She was often found in respiratory distress.

Since her heart surgery, she has enjoyed much better health. She has mild vision and hearing problems for which she wears corrective lenses and a hearing aid in one ear. She is very delayed in expressive communication. Her language comprehension, however, is excellent. Marianne and Anne have been instructed in signing to assist in communication. In addition, other forms of alternative communication are being explored, though speech continues to be a long term goal for Marianne.

Marianne attended day care for "early intervention" and as respite for Anne for three mornings a week, when she was three and four years of age. She experienced Kindergarten in the same day care center when she attended for five mornings a week, at the age of five. She attended grade one for two years in her neighborhood school. She now attends grade two in the same school. She reads and takes part in all primary school activities. In addition, she likes to swim and skate, to shoot baskets with her older brothers, and to play with friends in the neighborhood and at school.

c. Family #3

Sara and Phillip were married about six years ago. They are 31 and 29 years old, respectively. She is a recreation director in a program which serves adults with developmental disabilities and he installs furnaces. They have twin children, Shane and Margaret who were born in July of 1986.

At the time of their birth, Margaret appeared to be in good health but Shane was believed to have a mild heart defect. Very early in

Shane's life, Sara observed that he often made little jerking motions. When Sara called their family physician's attention to these, she got very little satisfaction. It was not until she used the word "seizure" that the behaviors were examined seriously. When Shane was five months old he was sent to the JB Children's Hospital in Regional Center, where it was decided that something was definitely wrong. Infantile spasms were ruled out and Shane was put on medication to control the seizures. When Shane was nine months old it was determined that his seizures were caused by neurofibromatosis.

As with most children with seizures, it took a lot of parental observation, patience, determination, and many interactions with physicians to find the right combination of medicines to give Shane seizure control and still allow him to be alert and functioning during his waking hours. In Shane's situation, both parents were involved in this monitoring and adjusting. Shane's seizures have been well controlled for about the last nine months. Since then, he has grown and developed at a rate which pleases his parents and his special teacher; but he is developmentally delayed. Most particularly, he is delayed in his ability to communicate. Margaret is developing normally.

Shane and Margaret attend the same day care where they are in a kindergarten program. Shane also receives early intervention services. His special needs teacher is teaching him to sign. Both parents and teachers communicate with Shane by way of words, gestures and signs. Shane's local school jurisdiction is making plans with Sara to admit Shane and Margaret to grade one in the coming school year. Plans are in place to provide appropriate support services for Shane when he begins school.

2. Interview Data

Interviews were transcribed, checked by the co-researchers, analyzed for themes of meaning; and then rechecked by co-researchers. Five principal themes emerged: The Children; Parental Stress/Anxiety; Services; Personal Comments; and Survival Strategies. Within these themes, thirty-four sub-themes were identified. Following are several examples from each category:

a. The Children

"A lot of Shane's behaviors are autistic...autistic-like behaviors in a child with neurofibromatosis...Sometimes he'll be off in a stare. I just tell him that he's going to be OK and say, 'Now, just relax.'"

"When I look at Bruce before he had friends in his life and just take a quick snapshot of what his life was like before...it was not a pretty picture. His whole life revolved around David and me. He also just wasn't the same person that he is today. He wasn't as assertive. It (having friends) just turned everything around. It's difficult to talk about it now. I used to be able to talk about it because it was so

fresh. Life without friends was all we ever knew. That's really distant for us, at this point. He never went anywhere unless he went with us. You know, the focus of his social life was a trip to the K-Mart on Saturday mornings. And I'm serious about that. He NEVER went anywhere."

"Marianne imitates those two boys (her brothers) an awful lot...an awful lot...in their actions and in their movements. She models their actions. For example, if they score a goal in hockey, or their wind-up when pitching a ball, or doing their homework, and things like that".

b. Parental Stress/Anxiety

"Even as Marianne gets older, we wonder will she ever be able to be left alone for a short time?...But with her communication problem, I don't think I would be comfortable enough to ever do that. I can't see babysitting ever ending".
"If I (Martha) were a foster parent, I wouldn't have to worry about going out working trying to make some money. They'd provide me with everything. I'd get so much respite care and I'd get money for looking after the child and everything. But if we ask them for anything for our own natural child that we try to keep home, it's a fight. The phone bills to Regional Center (when Bruce was sick) were just atrocious, $200-300 a month just to phone Regional Center."

"I (Sara) get depressed if I'm home twenty-four hours a day, seven days a week, that kind of thing. You can just get too depressed. I need that contact with the outside world. But I sometimes feel that I'm cutting myself up into too many chunks and not giving enough to everybody."

"...I can call and get the boys into hockey or anything. I can't do one bloody thing over that phone for Marianne. It's a meeting, then there will be another meeting and they take it to somebody else, for another meeting."

"They (the parents of children with disabilities) have enough to do. They can't do any more. But we don't get a whole lot of support unless we're willing to get out and fight and work for it."

c. Services

1. negative comments

"...The whole system just changes when you leave childhood and go into adulthood. The mentality of the social service system is more of a welfare mentality and you're treated differently. You really are. I felt it right away. We were getting children's services through the

family support program they have here. It was much more individualized. There was much more trust."

"A lot of professionals you deal with...you come home with the feeling of being disheartened. Of the majority of them I have dealt with I can honestly say that. That it's disheartening... Dealing with professionals makes my life very stressful."

"...She (speech therapist) gave me this (book) and said, 'Here do this.' And I just looked at it. It was a binder and it had a lot of information in it. You just can't do that to people, just go and hand them something and say 'Do this'...and not go over it with them and show them how it works, or how you can bring that stuff into your everyday life. It just felt like it was too much. It was going to be too hard to get the information out of it and it was going to take time from Shane (just learning how to do the stuff)...Anyway, I just would feel guilty about not doing it...Every time I looked at that (book) I felt guilty because I wasn't doing anything with him. But I just didn't didn't know how to go about doing it."

2. positive comments

"...one of the speech (therapists) in the Hanen Early Language Program, brought that book...that green book that the other speech therapist went and handed me...She brought that (book) alive. She showed how to integrate that into my life."

"Our pediatrician is a good support for us. Unfortunately he's retired (now) so that's a big loss right there to us."

"They (day care/early intervention) changed the system to accommodate Marianne, whereas I don't see that in the schools. ...She has to fit into their specific system, somehow."...(But) the grade one classroom that Marianne was in, with the regular teacher and the teacher assistant, signed to the class. They took it upon themselves to teach sign language right in the classroom. Ten minutes a day was allotted to sign language, to the point that those children, at the end of grade one, were almost fluent in sign language."
"...She does her best in her limited authority within the department to try to get things for Bruce. She will go to bat. She will take things up the line... So I have to say that Betty has been helpful. The difficulty is that once the wheels kick in, in terms of processing how things happen, Bruce just gets lost. I have a big problem, with how things have to be processed in that place."

"The club is competitive and they try to teach everyone to skate well; yet where Marianne has a problem in a certain area, they try other options that will give her success, as well."

d. Personal Comments

"...just to be able to sit there and talk about some of the things...Just the frustrations of dealing with doctors or with anybody. Just to be able to go and say, 'I feel like everybody's ganging up on me' (or) 'How could I let myself get that angry?' ...Just to be able to to go and say it makes me feel sad. I saw two kids running down the road and my son was standing in the driveway wanting to go too, but nobody asked him to go, and how it made him feel inside...to have that happen."

"I could use a little more action (support). Actual hands on type of things..."

"I guess my conviction. It would have to be that. I just so believe. And just my love for Bruce and...Well, I think the same holds true. I think just our ability to support one another, it helps to build on your own inner strength and your partners."

"I always felt there was something holding me back from totally loving him the way he should be loved...We couldn't make that communication. There just didn't seem...He and his father seemed to be quite good, you know. They bonded together quite good. But we couldn't seem to make that connection. I'd hold him and everything...I had a real problem with that, because I felt that something was holding me back...I think it was the fear that something was going to happen to him, that he was going to die. I didn't know what I was going to do."

"I had no choice. But no, I know I could never think that the burden was too much, even when she was so desperately sick. Those were hard times. Oh they were rough...nights and nights and nights of lost sleep...And you'd come home and you'd wonder what could I get for supper? The other ones are crying in your ear looking for something to eat. It was rough going, there's no doubt about it. But no, I'd never, ever tell anybody the burden's too great. You know, it took this two and a half years of physio, but when she took that first step on her own... It makes a difference, makes a big difference..."

"I wanted Margaret not to feel that all my time was spent with Shane. I knew that I needed help in order to make the balance so that I wasn't giving all my time with Shane and not Margaret. I realized that in our family we're going to have to have that extra support in order for us to make it..."

"Because, I just can't keep it up. I can't keep juggling it all...something is going to fall apart at some point."

e. Survival Strategies

"More and more I'm realizing that we have to work as a family and not just one person doing all the things. So now I'm feeling much more comfortable".

"...But one of the things that David and I never do is go to any meeting about Bruce without one another. We do not do it...If one's going to lose it, the other one can maintain composure and think about what to say next..."

"I try to work around them. I feel I have done that in my situation at school. The principal is not supportive of the endeavor of integration, and is just not going to be supportive. In my way, I worked around him rather than through him."

"I don't let things bother me because I've made up my mind that things are going to work out. Things will get better and that it's just a matter of slowing down and not getting in too much of a rush. The answers will come. You can get frustrated but talk about it instead of keeping it in. That's the most important thing for me. You have to talk about it and you have to let people know what's happening with you, even if it's not good. If it's really bad you still have to let it out instead of keeping it in. I need to talk out my feelings."

Additional Data

a. Questionnaires

Both Mothers and Fathers of the study families completed seven questionnaires from Dunst, Trivette, and Deal (1988):

1. Family Functioning Scale
2. Family Needs Scale
3. Family Resource Scale
4. Family Support Scale
5. Personal Network Matrix (Parts A and C)
6. Inventory of Social Support
7. Support Functions Scale

Responses support information provided by the co-researchers through their interviews. These families are closely knit AND support each other. Mothers have primary responsibility for running each household and providing child care, but study fathers assume considerable responsibility in these areas, as well. Each parent indicates "spouse" as his/her significant source of support. Spousal support is considered by all study parents to be an important factor in each family's success in daily living. Unfortunately, each family feels quite isolated and unsupported apart from the immediate family. This

feeling is more pronounced in the oldest family (followed closely by the next oldest family) and least pronounced in the youngest family. Study mothers indicate more demands placed on them, more isolation, more needs and more intense needs than do fathers. Study fathers, however, also indicate some needs and some feelings of isolation

In general, there is considerable within-couple agreement, though this is more apparent for the oldest pair (Martha and David) and least apparent for the youngest pair (Sara and Phillip). Family economic resources, likewise are more plentiful for the oldest couple and least plentiful for the youngest couple. Anne and Sam, the couple in the middle (age-wise) are also in the middle for within-couple agreement and availability of economic resources. All three couples have had to work very hard to get appropriate services for their children with special needs and have to continue monitoring these services. While all three couples maintain an optimistic attitude and look forward to the future with hope, all three have a degree of skepticism about services for their children. This skepticism is most apparent in the couple with the oldest child (Bruce) and least apparent in the couple with the youngest child (Shane). Marianne's parents fall somewhere in between.

2. MAPS Planning

Each family history and each study child's history has unique features. Yet there are many things that these families have in common. All speak of the period of adjustment the families went through at the time of each child's birth or return to the family. All three families coped with very serious illnesses with Bruce, Marianne and Shane. This continues to be a serious concern for Bruce's and Shane's families. All speak of the continuing struggle to get information and adequate services for their children. All speak, as well, of the rewards and satisfactions for the families and for individual family members; the opportunities for growth; and the development of new skills. These families have learned to do things that they never thought would have been possible. While the experience is demanding, and they get very tired; having a child with disabilities in their families has had its positive and rewarding side, too. But all three speak, as well, of needing some help and support that they are not now getting.

Each family dreams of as much independence as possible for their children and as much support as is necessary to help these children remain in the mainstream of life. They hope for the development of functional communication skills, friendships, normal social networks, meaningful work, security, success, and happiness for their children. All see school as the basis of education and training for their children and the source of learning opportunities that will help their children have meaningful adult lives.

Their nightmares are the opposite of their dreams. Any kind of institutional living, even group homes, are part of their nightmares. They don't want it. They don't want to see their children without friends and without personal support and encouragement. From their

perspective, they see institutionalization as the loss of whatever has been accomplished; the loss of skills and competence; the loss of friends and caring; the loss of rights; the loss of human dignity.

For these parents, and for many people currently in the children's lives, Bruce, Marianne, and Shane are real people with their own special learning problems; but they also have their own special talents, gifts and strengths. Each child is unique and each child can learn. Each child requires, however, adaptations and accommodations on the part of others in order to learn and to function well in the mainstream of society. It is possible for them to learn and to function; but they, more so than children without special needs, have a certain dependency on others. They need others to go a little further to understand them, to teach them, to include them into the life that we all enjoy. The parents find it very frustrating to have to be so dependent on the good will and cleverness of others.

When I listened to these families describe their ideal day for their children, I was impressed with the simplicity of the wants of these families. They are not longing for unrealistic changes. They all want less time to have to be devoted on getting ready for school and more independence in getting to school. Bruce would dearly love to ride a school bus. Marianne is just about ready to walk home from school by herself. Shane will be riding a school bus; but the family is hoping that he won't have to be strapped into his seat, that he'll sit with a buddy as he is supposed to sit. They all hope for the schools to capitalize more on their children's ability to learn from their social experiences. They hope for growth in their children's ability to communicate something about their day's experiences. They want their children to be included in at least some of the usual age-appropriate activities. They would like to be much less directly involved in seeing that their children have these opportunities. They would like someone in the lives of these children, other than their parents, who would do occasional special things with the children or see that they are included in some kind of a social life, some regular activities, and some spontaneous activities. They would like some of these social activities during the school week and some on the weekends. In short, their children's ideal days would include more "normal" age-appropriate experiences for their children and the acknowledgement by others of how important these kinds of experiences are to their children's growth and development.

Summary and Conclusions

This qualitative study helps us to see child disability from the perspective of the study parents, especially the mothers. Their stories indicate that these study parents do all the things that parents ordinarily do to help their children grow and develop, but they do these things more intensely and for longer periods of time. In addition, these parents spend a great deal of time getting and maintaining services for their children. These parents support each other and spell

each other in the child care and domestic tasks necessary for daily living. Each family obtains some degree of support from outside the immediate family, but most support is paid support, and much of it is not very helpful. These parents and especially the mothers indicate that they have many needs: relief from isolation; appropriate respite care; others with whom to talk about their struggles and their successes; time for themselves; freedom from exploitation; and freedom from having to advocate so much for services which rightfully should be a part of the everyday experiences of their children. While each acknowledges the demands on their lives which result from the disabilities of their special needs children, each acknowledges, as well, positive life experiences, opportunities for growth and many satisfactions from having a child with disabilities within their family circles.

Having indicated all of the above, the study begs the question: If these families, who represent so many mainstream attributes and skills, and if these mothers, intelligent, articulate, well-educated, and supported so well by their husbands, are having these many struggles in their efforts to look after their children in their own homes and communities; what is happening to women and children and families who do not "match" the mainstream so well? How are these people faring: culturally different families? sole-parent families? families whose primary caregivers are not so well supported? poor families? poorly educated families? inarticulate families?

Recommendations

Recommendations are presented under three categories: recommended attitude changes; recommended policy changes; and specific suggestions for service providers. The suggestions for service providers read like guidelines for "best practices" (see Johnson et al, 1989). None of these recommendations is beyond the scope of service providers at this time.

1. Attitude changes

a. societal

Disability is part of human existence. Some of us are born with disabilities; some us become the parents of disabled children; some of us become disabled. It is a normal risk of life. People with disabilities, whether children or adults, are a part of us. We must be prepared to help disabled people live and work among us.

The parent who is the principal household organizer and caregiver is as valuable in contribution and expertise as is the parent who is the principal provider of economic resources for the household.

b. professionals

People with disabilities are a part of the normal spectrum of humanity. We are paid to help people because we have knowledge and skills that are of value for the optimum development and the quality of life of the clients who come to us. People with disabilities are our responsibility as much as any other clients.

Parents of disabled children are a rich source of information and experience concerning their children. We will be most effective, as professionals, if we learn to work with parents and learn to include them into the planning, goal-setting, and decision-making concerning their children.

Even though it is imperative that we work WITH parents, the responsibility for the development and monitoring of programs and services is ours. We know who the clients are, and through planning with the parents, what services they need now, and will need in the future. It is our responsibility to see that appropriate services are available without having to be "pressured" by parents. Parents have enough to do.

Our response to the parent who is the primary household organizer and caregiver should be as respectful and responsible as it is to the parent who is the principal provider of economic resources to the family. Similarly, we should be respectful and responsive to the parent who is the sole parent in any household. In all cases, we need to be mindful of the time and energy demands which parents face.

2. Policy Changes

Because of the benefits to both those with disabilities and those free from disabilities, life in the mainstream is the option of choice, as much as possible, for all human beings.

A system of financial equity must be created in order to minimize the differences between natural and adoptive parents' financial risks when parenting a child with disabilities as compared to foster parents' risks. This is especially important with reference to natural and adoptive parents who care for an adult child.

Provisions for more respite care, especially in the client's home; more direct support in meeting the daily needs of clients; and more specific support in meeting the social and recreational needs of children and adults with disabilities are desperately needed.

Provisions for adequate, affordable, and reliable child care as an option for families, is basic to any kind of equity in quality of life for all parents. This is especially important for parents of children

with disabilities, some of whom require specific kinds of child care for much longer periods of time, sometimes for a lifetime, than do children without disabilities.

3. Service Providers

Work WITH parents, valuing them and their contributions and ideas; acknowledge their expertise.

Start with the positive. Celebrate the child and her competence. Only then, move into the child's areas of need and how parents and service providers can help the child.

Don't overwhelm parents; don't dishearten parents. They are aware of the child's limitations. Provide information and ask parents about what they know; what they think. Focus on two or three achievable goals. Support parents. Try to see the situation from the point of view of the family. Look at the whole child and look at him within the context of his family. See the child first and then look at the disability.

Try to appreciate what it means to be responsible for the child's care 24 hours a day, seven days a week. Contemplate alternatives. Would the child REALLY be better off? All indications assure us that children grow and develop best at home. Give parents a hand.

When parents are asked to work on skill development, select skills that are truly appropriate and useful and which make sense to the child. Ask the parents, "What do you think?" "Would it be possible to work on this? Do you have the time? Will it work into your family's schedule? Would acquiring the skill be helpful and useful?" Ask parents to provide feedback on the process. Don't be afraid to admit error. Do be willing to rewrite the plan. If the child fails, ask, "Could there be reasons for failure other than simply parental disinterest, incompetence, or neglect?"

When planning programming and making professional suggestions ask, "How can we use this family's strengths? How can we avoid making any family members feel left out? What information and supports have to be in place in order to avoid failure, and especially, in order to avoid disaster?"
Be prepared to change "the system", or the school, or the classroom, or whatever, to meet the child's needs; do not expect the child to make adaptations to fit into what "the system", or the school, or the classroom, currently has to offer.

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